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The Experiences of Siblings of Individuals with Disabilities: A Holistic View

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The Experiences of Siblings of Individuals with

Disabilities: A Holistic View

A Dissertation by

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Submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy in Education

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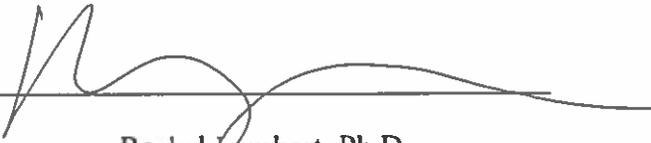Committee in Charge:

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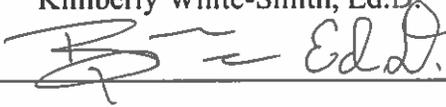The dissertation of Ashley N. Mc Adams is approved.

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The Experiences of Siblings of Individuals with

Disabilities: A Holistic View

ABSTRACT

The Experiences of Siblings of Individuals with Disabilities: A Holistic View

by Ashley N. Mc Adams

The research on siblings of individuals with disabilities has rarely addressed the perceived benefits of having a sibling with a disability. The existing research on the experience of siblings of persons with disabilities is also limited to European American families (Sage & Jegatheesan, 2010). With families from different cultures, I sought to capture the experiences of brothers and sisters who have siblings with disabilities. The purpose of this paper is to analyze the relationships of siblings with disabilities and typical developing siblings, and present a holistic picture from the perspective of the typical developing siblings. These gaps in the literature will be addressed by interviewing siblings about their experiences of coping with adversity, the perceived benefits of having a sibling with a disability, and how the perceptions of the person with a disability by professionals, parents, and other family members has impacted their experiences. Participants were recruited from a pool of persons already known to the researcher and through a "snowball" approach (Hays & Singh, 2012), resulting in a heterogeneous group of eight participants. Interpretive phenomenology was the theoretical lens used for this study, as the purpose of it is to interpret and understands one's described experiences. A semi-structured interview protocol was used to interview each of the participants three times. Themes emerged in the areas of the challenges of having a sibling with a disability, coping with those challenges, and perceived benefits of having a sibling with a disability. Lastly, messages for families, educators, professionals and future researchers are shared.

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Chapter I

The Experiences of Siblings of Individuals with Disabilities: A Holistic View

I am an African American woman interested in studying the experiences of

having a sibling with a disability. I became interested in learning about having a

sibling with a disability when I was working as a developmental specialist for a

private clinical agency and then later as a behavior interventionist for a public school

district. Working in these positions, I provided behavior interventions for students

diagnosed with developmental delays in their school, home, and community.

When I met the siblings of the children I worked with, I observed their

interactions with one another. I wondered how they felt about having a sibling

diagnosed with a disability and who received several services throughout the week.

Because I worked in the home, a bond was created between the family and me,

including the siblings. I would sometimes include the sibling without a disability in

therapy sessions. For example, I would have their siblings model appropriate play

activities with play sets such as doll houses or race tracks. Then the children

receiving therapy would imitate their siblings to learn how to play appropriately with

the toys. The siblings without disabilities would talk to me and ask me questions

about why I was in their home and playing with their brother or sister. They would

show interest in me and would want me to "play" with them too.

The longest I have worked with the same family was for approximately two

years. I learned a lot about that family's structure and the relationship between the

child with a disability and the sibling without a disability. The sibling in this family

without a disability was about ten years older than the child with a disability. They

had a very loving relationship and the sibling without a disability was very

understanding and patient with her sibling. There were some instances when they would have disagreements, but those were definitely exceptions to their typical interactions.

As an outsider looking into this sibling relationship, I admired it and developed a desire that other sibling relationships that include an individual with a disability would mirror that relationship. In other families, I have seen sibling relationships that were not as positive. These and other experiences of working with students with disabilities that have siblings informs my research, which focuses on providing an opportunity for them to share their experiences, including both the challenges and benefits of having siblings with disabilities.

The Purpose of the Study

Approximately 6.4 million children and youth ages 3-21 years old reportedly received special education services during the 2012-2013 school year (National Center for Education Statistics, 2015). In 2012, it was self-reported that 20.9% of adults in California have a disability (Center for Disease Control and Prevention, 2014). Disability is identified as having an impact on an individual's vision, movement, thinking, remembering, learning, communicating, hearing, mental health, and social relationships (Center for Disease Control and Prevention, 2014). Looking at these numbers based on age, sex, and race/ethnicity the percentages vary between categories (Center for Disease Control and Prevention, 2014). The percentage of adults that self-reported having a disability range in age with 13.0% of the adults being 18-44 years of age, 26.7% of the adults being 45-64 years of age, and 35.3% of the adults being 65 years of age or older (See Table 1). It was reported that 20.1% of men and 21.7% of women had a disability

(See Table 2). It was reported that 24.3% of white, 30.9% of black, 18.1% of

Hispanic, 11.7% of Asian, 44.5% of American Indian or Alaska Native (AIAN),

and 30.2% of other/mixed race had a disability (See Table 3).

Table 1. Age and Disability Status			
	18-44 year olds	45-64 year olds	65+ year olds
Disability	13.0%	26.7%	35.3%
No Disability	87.0%	73.3%	64.7%

Table 2. Sex and Disability Status		
	Men	Women
Disability	20.1%	21.7%
No Disability	79.9%	78.3%

Table 3. Race/Ethnicity and Disability Status						
	White	Black	Hispanic	Asian	AIAN	Other
Disability	24.3%	30.9%	18.1%	11.7%	44.5%	30.2%
No Disability	75.7%	69.1%	81.9%	88.3%	55.5%	69.8%

Based on the self-reported information, most of the individuals that have a

disability are in the 65+ year-old age range. There was minimal difference between men

and women that reported having a disability. American Indian/Alaska Natives and Blacks

had the highest percentages of disabilities.

In reviewing the prevalence of disability among individuals in California it is vital

to consider the experiences of the siblings of these individuals with disabilities. I'm

especially interested in not only the adversity siblings experience but also their positive

experiences. Through my review of the literature it has become evident that the research

on siblings of individuals with disabilities has rarely addressed the benefits of having a

sibling with a disability. The existing research on the experience of siblings of persons

with disabilities is also limited to European American families, yet the prevalence of

disabilities is higher among other races/ethnicities based on the 2012 self-reported data (Sage & Jegatheesan, 2010).

The purpose of this dissertation is to explore the experiences of siblings of individuals with disabilities by interviewing them about their ways of coping with adversity, the perceived benefits of having a sibling with a disability, and how the perceptions of the person with a disability by professionals, parents, and other family members has impacted their experiences. In addition, I sought to capture the experiences of brothers and sisters of different cultural backgrounds who have siblings with different disabilities.

Theoretical Framework

To accomplish this, the methodology is framed by a phenomenological perspective. Established by Edmund Husserl and others in the beginning of the 20th century, phenomenology is characterized as a philosophy that studies lived experiences and analyzes what these experiences consist of (Moran, 2000; Dowling, 2007). More specifically, interpretive phenomenology was the specific theoretical lens used for this study. The purpose of interpretive phenomenology is to "describe, understand and interpret participants' experiences" (Tuohy, Cooney, Dowling, Murphy, & Sixmith, 2013). There have been few studies that have allowed siblings of persons with disabilities to explore the meanings of their experiences. In addition, most research has focused on the adversity faced by siblings of persons with disabilities. My goal is to capture a more holistic picture of these lived experiences.

Research Questions

Specifically, my research will address the following research questions:

1. *How do individuals describe coping with the challenges of having a sibling with a disability?*

2. *How do individuals describe the benefits or advantages of having a sibling with a disability?*

Assumptions and Caveats

The participants in this study consist of individuals that have a sibling with a disability. They are from a diverse ethnic and cultural background and are at least 18 years of age. The participants were recruited through snowball sampling and some participants were already known to the researcher. They were initially contacted by phone and/or e-mail communication. Although the participants were selected from a diverse population of siblings of individuals with disabilities, the results may not be representative of the entire population. In addition, since there is limited literature reflecting the holistic experiences of having a sibling with a disability, this study may be considered an opening to giving this population a voice and platform to share their experiences.

Summary

In order to answer the question about how professionals, parents and other family members perceive persons with a disability and how that impacts the experiences of siblings of persons with disabilities the literature about family studies will be reviewed. In an effort to answer the question about how individuals describe coping with the challenges of having a sibling with a disability, the literature regarding coping strategies, internal factors and protective factors will also be considered. In addition, firsthand experience from siblings of individuals with disabilities that describe the benefits or advantages of having a sibling with a disability and the significance of culture will be discussed in the following chapter.

Chapter II

Literature Review

Reviewing Sibling Experiences

As stated above, the purpose of this dissertation is to explore the experiences of siblings of individuals with disabilities by interviewing them about their ways of coping with adversity, the perceived benefits of having a sibling with a disability, and how the perceptions of the person with a disability by professionals, parents, and other family members has impacted their experiences. Being a sibling of an individual with a disability is complex and can be understood from a multitude of perspectives. Oftentimes the experiences of siblings of individuals with disabilities are overshadowed by the experiences of parents or the persons with disabilities themselves. Given this, one overarching goal of this study is to give voice to the experiences of siblings. In an effort to understand the sibling's position, it is necessary to consider the family structure.

Family studies are significant to me because it is necessary to consider the family structure in which the child is raised prior to exploring the sibling relationship(s) because it may have an impact on how siblings perceive disability. It is also important to consider one's cultural background as it may also impact how individuals interact and perceive individuals with disabilities. Having the foundational background of the system in which the child exists lays the groundwork for exploring the specific experiences of sibling relationships.

The following topics will be discussed as the literature is reviewed: The siblings' roles in the family, experiences with professionals and school systems, long-term care, resilience, and significance of culture. The researcher selected these specific areas of the

literature to review because they are the different arenas of life that the participants in this study shared when discussing their experiences in having siblings with disabilities.

The Sibling's Role

Being a sibling of an individual with a disability has an impact on the role in the family of the individuals without disabilities. The following studies discuss the siblings' involvement in extracurricular activities, responsibilities in the home, influence on career choices, and the relationships between siblings without disabilities and their siblings with disabilities. According to Barak-Levy, Goldstein, and Weinstock (2010) where 27 parent self-reports were compared to 27 self-reports of siblings of children with disabilities and 27 self-reports of siblings of children without disabilities, siblings of individuals with disabilities have been found to participate in fewer extracurricular activities than their peers. Their peers that do not have a sibling with a disability may be part of football leagues for the city or participate in dance recitals, but the sibling of the individual with a disability is often involved in fewer of these types of activities. Instead, they help their siblings and have additional responsibilities in the home. The parents perceive these responsibilities as positive for the child but the siblings themselves perceive it as a source of emotional distress (Barak-Levy, Goldstein, & Weinstock, 2010). The authors suggest that counselors and/or parents should support siblings in decreasing their levels of stress by reducing parental expectations of responsibility and aiding in increasing their participation in extracurricular activities outside of the home.

Contrary to the conclusions of Barak-Levy, Goldstein, and Weinstock (2010), Marks, Matson, and Barraza (2005), in a study involving interviews with seven siblings about their decision to enter special education as a career, found that when the sibling without a disability has responsibility for the brother or sister with a disability there can

be a positive impact such as leading them to select a profession related to improving practices for individuals with disabilities. When the parents also reinforce the close sibling relationship, this may have an influence on the sibling choosing a career that involves individuals with a disability (Marks, Matson, & Barraza, 2005).

In a study that involved 90 siblings who completed questionnaires, the relationships between siblings without a disability and their siblings with diagnoses of autism or Down syndrome compared to relationships between typically developing siblings found that the individuals that have a sibling with autism or Down syndrome admired their sibling more and were less competitive and argumentative with them than individuals with a typically developing sibling (Kaminsky & Dewey, 2001). In addition, siblings of individuals with autism were found to feel less lonely and adjusted to the dynamic well (Kaminsky & Dewey, 2002). This finding is similar to the finding of Macks and Reeve (2007) who concluded that the psychosocial and emotional development and adjustment of the non-disabled siblings, involving 86 parents that completed questionnaires about their child, were strengthened as a result of having a sibling with autism.

Although research (Kaminsky & Dewey, 2001; Macks & Reeve, 2007) suggests that having a sibling with a disability can lead to a cohesive sibling relationship and positive adjustment, Kaminsky and Dewey (2001) report that there is less intimacy, prosocial behavior, and nurturance in the relationship of siblings with autism compared to having a sibling with Down syndrome or one that is developing typically. The findings in the research of Petalas, Hastings, Nash, Lloyd and Dowey (2009), where 49 mothers of children with disabilities completed ratings scales, are compatible with those of Kaminsy

and Dewey (2001) in that Petalas et al. (2009) found that siblings of individuals with both an intellectual disability and autism had a higher number of emotional problems when compared to siblings of children with only an intellectual disability. Furthermore, having a sibling with autism can have more of a negative impact on the sibling without a disability as demographic risk factors, such as number of siblings, increase (Macks & Reeve, 2007). Additionally, a sibling of an individual with autism is more likely to develop internalizing problems such as depression or anxiety than a child in a family with a typically developing sibling, according to a study involving 25 mothers that completed questionnaires; yet, the cause of this is unknown (Ross & Cuskelly, 2006).

Orsmond and Selzter (2000), in a longitudinal study with 461 families, investigated the differences and similarities of brothers and sisters with siblings with intellectual disabilities. They found that brothers scored lower than sisters on measures of caregiving, companionship, and positive affect. Other gender differences included brothers having a more favorable response to their brother with intellectual disabilities compared to brothers of sisters with intellectual disabilities. In a different study, the same authors (Orsmond & Seltzer, 2009) studied the well-being of siblings of individuals with autism using a diathesis-stress model with 57 families. They found that sisters had higher levels of depressive and anxiety symptoms than brothers. In addition, autism characteristics in combination with a high number of stressful events led to depressive and anxiety symptoms in siblings while a family history of autism was connected with depressive symptoms but not anxiety symptoms (Orsmond & Seltzer, 2009).

This section reviewed the siblings' involvement in extracurricular activities, responsibilities in the home, influence on career choices, and the relationships between

siblings without disabilities and their siblings with disabilities. As discussed, siblings seem less involved in extracurricular activities and more involved in responsibilities in the home. It was noted that some of the siblings select a career that is related to working with individuals with disabilities based on the influence of their brother and/or sister. Lastly, a variety of differences and similarities in life experiences of having a sibling with disabilities versus without disabilities was discussed. Next, the experiences that families of individuals with disabilities have with professionals and school systems will be reviewed.

Experiences with Professionals and School Systems

When individuals have disabilities, their experiences and their families' experiences with professionals and the school system are often quite different than those of individuals without disabilities. The following section will discuss how a parent interacts with her son's medical team, deciding on medical advice, and the schools' interactions with children with disabilities.

McCloskey (2010) discussed how a parent of a preschool student with disabilities interacts with her son's physicians, teachers, and therapists. She was an active member of the team which was appreciated by the professionals and the school system. Yet, she noticed that in the school district meetings she was not seen as an expert; instead she was just seen as *the mother*. Whereas, when the service provider such as the occupational therapist spoke, the team seemed to listen more than when the mother spoke. Additionally, although the mother wanted to advocate for the best services for her son she felt the need to hire a lawyer to ensure that this took place. She was concerned, however,

that this process may have a negative impact on the school's interactions with her son. Therefore, she felt like she was in a dilemma (McCloskey, 2010).

The mother also expressed the difficulty of juggling medical advice from different physicians (McCloskey, 2010). She took it upon herself to research different approaches that physicians had to sensory integration. She was very impressed by videotapes that one physician showed her regarding his treatment approach. Yet, her son's neurologist explained that the videotapes may have been a skewed view of that physician's treatment outcomes. This led her to negotiating her position within her relationship with the neurologist to respect both physicians' philosophical approaches (McCloskey, 2010).

Furthermore, Ballard, Bray, Shelton, and Clarkson (1997) explained that children with disabilities are often rejected at early childhood centers and schools. Also, parents experience stress when it is a challenge to find resources. On the contrary, when professionals and educational settings are supportive it is a contributing factor to the family's well-being and the development of the child with a disability (Ballard, Bray, Shelton, & Clarkson, 1997).

As mentioned, this section covered how a parent interacts with her son's medical team, deciding on medical advice, and the schools' interactions with children with disabilities. These are some of the many experiences that parents of individuals with disabilities have when interacting with professionals and the school system. Another element to review is the complex decision regarding long-term care of individuals with disabilities.

Long-Term Care

An area to consider is that of the long-term care of the sibling with a disability. As the life expectancy of individuals with disabilities has grown, the likelihood of siblings becoming the caretaker has increased (Burke, Taylor, Urbano, & Hodapp, 2012). According to a self-report survey completed by siblings, they were more likely to be expected to assume more of a care-giving role if they were female, had closer relationships with their siblings, and were the only other children in the family. An additional predictive factor of siblings assuming care-giving responsibilities of long-term care is communication (Griffiths & Unger, 1994). Being part of the process and having the discussion with their parents about future planning for the long-term care of their sibling with a disability made it more likely for them to be willing to take on that responsibility.

In addition to reviewing the literature about family studies, the sibling's role within the family, experiences with professionals and school systems, and long-term care literature should also be reviewed, in an effort to gather a solid foundational background regarding the topic of siblings of individuals with disabilities, including resilience, coping strategies, and the significance of culture. The objective of the remainder of this literature review is to look at that additional literature.

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Resilience

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In order to discuss the perceived benefits and challenges of having a sibling with a disability, a frame for understanding this is necessary. Resilience provides that frame. Resilience is defined as "… the capacity to rebound from adversity strengthened and more resourceful. It is an active process of endurance, self-righting, and growth in

response to crisis and challenge. The ability to overcome the blows of outrageous fortune challenges our culture's conventional wisdom: that early or severe trauma can't be undone…" (Walsh, 1998). The process of fostering resilience is reflected when an individual overcomes adversity and applies their experiences to future situations that in turn become favorable and advantageous for them.

Wright, Masten, and Narayan (2013) outlined how the study of resilience has become evident in four major waves of research. The first wave was *Identifying Individual Resilience and Factors that Make a Difference*. This early research about resilience focused on "that Horatio Alger ability to 'pick oneself up by one's own bootstraps" (p. 16). While the first wave focused on one's own efforts to identify individual resilience, the second wave was *Embedding Resilience in Developmental and Ecological Systems, with a Focus on Process* (Wright, Masten, & Narayan, 2013). This wave included more of an emphasis on relationships and systems to study resilience. The third wave was *Intervening to Foster Resilience.* Experiments focusing on the change process were one of the key works in the third wave of research on resilience. Wright, Masten, and Narayan (2013) identified the fourth wave as *Resilience Research on Multiple-Systems Levels, Epigenetic Processes, and Neurobiological Processes.* This wave is heavily influenced by neurobiological adaption, brain development, behavior, and many process linking genes on multiple levels.

Promoting Resilience Among Families

In addition to identifying the research of resilience, it is necessary to highlight ways to promote resilience among families because siblings of individuals with disabilities may benefit from them. Sheridan, Sjuts, and Coutts (2012) name four ways to

promote resilience: (1) base intervention efforts on family-identified needs, (2) use existing family strengths and capabilities to mobilize family resources, (3) maximize social networks and supports, and (4) use helping behaviors that promote the acquisition of competencies. These are beneficial ways to promote resilience for siblings of individuals with disabilities.

Even though having a sibling who is diagnosed with a disability may come with challenges, there are siblings that experience positives in their relationships and foster resilience over time. The following discussion is about the disability of autism. For example, some of the positive impacts of having a sibling with autism include having a close sibling relationship along with family cohesiveness, resilient families, as well as an awareness and sensitivity towards children with autism (Bayat, 2007; Kaminsky & Dewey, 2001; Meyer & Vadasy, 1994; Orsmond & Seltzer, 2000). Additional positive qualities of having a child with autism include the opportunity for the sibling to gain experience volunteering, being a caretaker, and modeling appropriate interactions (Marks, Matson, & Barraza, 2005; Ferraioli, Hansford, & Harris, 2012). Siblings of students with autism tend to have a better self-concept than individuals without a sibling with autism and their career path is influenced by the child with autism (Marks, Matson, & Barraza, 2005; Macks & Reeve, 2007).

In addition to the aforementioned positive impacts, others include an increase in family cohesion and a decrease in sibling rivalry (Kaminsky & Dewey, 2001; Meyer & Vadasy, 1994; Orsmond & Seltzer, 2000). Bayat (2007) found that siblings of a child with autism have close relationships with each other. It was also found that the sibling without autism may sacrifice their time: "Autism has made us stronger and more

cohesive. My children are very protective of their sister even though juggling is common and sometimes important events are missed" (Bayat, 2007).

In addition to having a cohesive relationship as a result of a sibling being diagnosed with autism, families also display their resiliency by making positive meaning from the experience of having a child with a disability (Bayat, 2007). Bayat (2007) found that the families tend to show appreciation for the smaller gifts of life and have a general positive perception of life. Another positive impact is that siblings of a child with autism may become more sensitive and compassionate towards individuals that have disabilities and they may spread this experience with peers (Bayat, 2007). A sibling reflects on how he has become more sensitive, accepting, and caring as a result of the impact his brother had on him:

A 12-year-old sibling of a child with autism said, 'I don't think I would've been as sensitive if I didn't have [my brother]. When my friends make fun of "retards," I tell them not to. I think I accept differences better as a result of this.'

Another sibling, 13 years old, expressed her feelings in a similar way:

I've definitely become more aware of people in general. I love my brother to death, and I know that I've become a more caring person because of him.

Internal factors that have been identified in youth that are resilient include good intellectual functioning, greater self-esteem, and self-regulation (Buckner, Mezzacappa, & Beardslee, 2003). This was the case for very low income families in Buckner, Mezzacappa, & Beardslee's (2003) study that investigated the characteristics that separate resilient from nonresilient school-age youth. Siblings of individuals with

disabilities may have also acquired these traits. Learning of their experiences through their shared stories will determine if that is so.

Marks, Matson, and Barraza (2005) conducted a study to find out about the experiences of siblings of individuals with disabilities. The participants shared their experiences in a focus group and individual interviews. It was shared that the role of being a sibling of a child with autism provided the opportunity for the sibling to be able to gain experience in volunteering (Marks, Matson, & Barraza, 2005). A sibling explains his role while growing up with a brother diagnosed with autism:

Well, growing up, when they asked for volunteers for the program that the parents were involved with, whether it was a bowling activity or a day camp, I did work in that. Like, they had a summer day camp thing going for the kids.... And, you know, you're always asked to do stuff with [Kevin]. You know, to take him to the store with me and just because my mother wanted him to get out and be included. That was a very big thing and source of sadness for her, as a parent, when she would see other kids who had friends and social relationships (Marks, Matson, & Barraza, 2005).

The same sibling discussed how he has a close relationship with his brother and cares for him on a daily basis (Marks, Matson, & Barraza, 2005). Now that they are adults they live in different locations, yet the siblings speak daily and visit each other. He stated, "He only lives about 8 blocks from me, and I see him every day, but, he likes being around other people as long as he has his own space to control. And, he likes coming over. He comes over every Sunday for dinner and he likes doing that. And he likes visiting" (Marks, Matson, & Barraza, 2005). It has been noted in research literature

that the sibling of a child with autism may tend to take on the role of a caregiver. As they

mature they may even serve as teachers or mentors (Cuskelly & Gunn, 1993; Stoneman,

2005).

Being a sibling of a child with a disability can also have an impact on the career

path of the sibling without a disability. Marks, Matson, and Barraza (2005) found that

siblings have a desire to make improvements in the areas of services provided to

individuals with disabilities. They also may join the field of special education to expand

from teaching in the classroom to explore conducting research. One of the siblings in the

study chose to pursue a degree with a dual major in elementary and special education.

Her goal was to learn and educate others about individuals with disabilities. Her main

objective for teaching students with disabilities was to help them develop the necessary

skills to be independent and productive citizens in the community (Marks, Matson, &

Barraza, 2005). In addition, she would like to have a discussion with general education

teachers about seeing the strengths in students with disabilities (Marks, Matson, &

Barraza, 2005). Another sibling that was influenced by having a sibling with a disability

to pursue a career in education and teach students in college about disabilities had a clear

goal for doing so:

> I wanted to force students to move beyond thinking of people in stereotyped
>
> ways and instead see them as psychological beings every bit like themselves,
>
> with the same needs in every aspect of their lives. I wanted them to challenge
>
> every assumption being any instance of segregated activity or living and ask,
>
> 'Why should things be done this way or that way? (Marks, Matson, & Barraza,
>
> 2005).

When developing and implementing a treatment plan for a child with autism, their sibling may be interested in participating in the process. The sibling without autism can facilitate positive interaction between themselves and their sibling. These positive interactions may include greetings and initiating play. This may help the student with autism learn how to generalize these skills from their sibling to the educational and community settings (Ferraioli, Hansford, & Harris, 2012). These interactions may not only benefit the child with autism for the purposes of learning; they may also provide the opportunity for the sibling to use the time to interact with and explore the skills and qualities within their sibling with autism (Ferraioli, Hansford, & Harris, 2012).

Siblings of children with autism are not at risk for loneliness (Kaminsy & Dewey, 2002). In the families where they attend support groups, the siblings without autism may be more likely to interact with children with autism in other families according to Kaminsky and Dewey (2002). Being a member in a support group may also have a positive impact on social adjustment for the sibling without autism (Kaminsy & Dewey, 2002). Having a sibling with autism also has a positive impact on an individual's perception of themselves compared to individuals without a sibling with autism (Macks & Reeve, 2007). The sibling without autism has a positive perception of their scholastic performance, intelligence, behavior, and anxiety (Macks & Reeve, 2007). Each of the aforementioned traits may serve as protective factors that assist in successful adaptation to adversity and being instrumental in them overcoming it.

It is possible for the sibling to have a positive impact on the life of the child with a disability (Reagon, Higbee, & Endicott, 2006). This can happen through close sibling relationships along with family cohesiveness, building resilient families, and being aware

of and sensitive towards children with autism (Bayat, 2007; Kaminsky & Dewey, 2001; Meyer & Vadasy, 1994; Orsmond & Seltzer, 2000). Gaining experience volunteering, being a caretaker, and modeling appropriate interactions as the sibling without autism are also positives (Marks, Matson, & Barraza, 2005; Ferraioli, Hansford, & Harris, 2012). Other positive qualities include siblings of students with autism tending to have a better self-concept than individuals without a sibling with autism and having their career path influenced by the child with autism (Marks, Matson, & Barraza, 2005; Macks & Reeve, 2007).

This section has outlined several positive impacts, qualities, or outcomes of having a sibling with a disability. When the sibling uses his/her resources from the context of being raised with an individual with a disability and applies it in settings that in turn become favorable and advantageous for them, the process of fostering resilience is reflected.

Coping Strategies

In connection with promoting resilience with families as discussed above, considering how families cope with having a child with a disability is discussed because the outcome of their coping strategies may detail how they overcome adversity. Altiere and Kluge (2009) examined the ways families coped with having children that have autism. The variables they looked at to evaluate relationships among family members included cohesion, adaptability, and social support. There were a total of 52 participants that included 26 pairs of parents (mothers and fathers). The *Family Adaptability and Cohesion Evaluation Scales-III* was used to gather the participants' responses. The *Family Adaptability and Cohesion Evaluation Scales-III* is a self-report questionnaire

with 40 items that measures "a family member's perceived and desired family cohesiveness and adaptability to change" (Altiere & Kluge, 2009).

The responses of mothers and fathers were compared. Both mothers and fathers were consistent with responses for each variable except for how they perceive the amount of social support they receive from family and friends. Mothers perceived themselves to have more social support than the fathers. Altiere and Kluge (2009) also noted that fathers reported that they lost friends as a result of their friends not understanding the struggles of raising a child with autism. Furthermore, friendships were broken with the father's friends because he was not able to spend as much time socializing with them. Families with a child that has a disability have higher levels of positive coping and cohesion, which are associated with adaptability (Altiere and Kluge, 2009).

While Altiere and Kluge (2009) reported that families with a child that has a disability have higher levels of positive coping and cohesion, Pottie and Ingram (2008) examined coping, stress, and well-being of parents with children with autism. There were a total of 93 participants in the study. There were 60 mothers and 33 fathers which made up 69 families and 24 of the families had both parents participate (Pottie & Ingram, 2008). A measure was used to analyze the effects of coping on daily psychosocial distress and well-being in parents of children with autism. Over a 12-week period, two times per week the parents reported their daily stress, coping responses, and end-of-day mood.

The results indicated that predictors of positive moods were social support, positive reframing, emotional regulation, problem-focused, and compromise coping defined as "working out a compromise between the priorities/needs of the individual and the limits of the stressful situation" (Pottie & Ingram, 2008). The predictors of a negative

mood include blaming, withdrawal, escape, and helplessness coping. Contextual factors that were found to have an impact on positive mood consist of distraction and emotional regulation coping. Parents do indeed engage in different coping behaviors as they raise their child that has been diagnosed with autism (Altiere & Kluge, 2009; Pottie & Ingram, 2008).

Protective factors that have been found to contribute to successful adaptation to adulthood for individuals with learning disabilities compared to individuals without learning disabilities are maternal education beyond high school, rules and structure in the household and supportive adults who value trust (Werner, 1993). Being aware of these protective factors as I listen to the experiences of sibling of individuals with disabilities, it would be interesting to find out if these are protective factors they identify as being instrumental in them overcoming adversity.

Significance of Culture

As mentioned in the previous chapter, considering the cultural background of the family is meaningful because it may impact how they perceive individuals with a disability. Among other things, culture influences how families respond to having an individual with a disability in their home. Culture can be defined in different ways and, depending on the definition, it can be viewed as having different influences on the lives of individuals with disabilities. For example, Quest Rapura defines culture as:

Culture is what holds a community together, giving a common framework of meaning. It includes how people communicate with each other, how we make decisions, how we structure our families and who we think is important. It expresses our values towards land and time and our attitudes towards work and

play, good and evil, reward and punishment. Culture is preserved in language, symbols and customs and celebrated in art, music, drama, literature, religion, and social gatherings. It constitutes the collective memory of the people and the collective heritage which will be handed down to future generations (Quest Rapura, 1992, p.7).

Culture influences individuals with disabilities. As defined, a culture has a common framework of meaning. Therefore, how different cultures make meaning of disabilities is to be considered. The definition of culture also speaks to the family structure and who is deemed important. This interpretation may have a direct impact on individuals with disabilities and how they are positioned within the family. Smedley and Smedley (2005) discuss other ways culture can be defined.

Smedley and Smedley (2005) discuss the anthropological and historical perspectives on the social construction of race. They explain that anthropologists consider the definition of culture in a different way than E.B. Tylor's 1871 textbook definition. E. B. Tylor (1871) defines culture as "that complex whole which includes knowledge, belief, art, morals, law, custom, and any other capability and habits acquired by man as a member of society." On the other hand, the anthropological perspective argues that culture is external, acquired, and transmissible to others. Their mindset is that culture is not innate. Instead, culture is socially constructed through acquired traditions of thought and behavior (Harris, 1999). Anthropologists declare that humans are only born with the capacity to learn and construct culture, not culture itself. The capacity they are referring to is in large part language. Although language facilitates the social construct of culture,

it is not the only avenue to acquire culture. Culture is highly influential in that it dictates the type of person we become and our belief system (Harris, 1999).

The distinction between culture and ethnicity is made by Smedley and Smedley (2005). Ethnicity is defined as groups of people with similar culture traits that are differentiated from other people. For example, an ethnic group may consist of people who have language, place of origin, values, beliefs, and religion all in common (Jones, 1997). Since ethnicity and ethnic groups are not definite constructs, they may change over time. While culture traits are learned, an ethnicity can be adopted by other individuals.

Ravindran and Myers (2012) discuss the ideology of culture from the lens of how it influences perceptions of health, illness and disability. Comparable to Smedley & Smedley's (2005) discussion about culture, Ravindran and Myers (2012) explain that beliefs within a culture may change over time. The lives of individuals with disabilities largely depend on the culture of their families and communities. Major factors that culture influences include treatment approaches, relationships between family and professionals, and community understanding of individuals with disabilities (Ravindran & Myers, 2012).

Artiles, Kozleski, Trent, Osher, and Ortiz (2010) reported that there are a disproportionate number of historically underserved individuals identified as needing special education services. The authors are using the term *historically underserved groups* in a way that describes "students from diverse racial, cultural, linguistic, and economically disadvantaged backgrounds who have experienced sustained school failure over time" (Artiles et al., 2010).

Aside from the issue of disproportionate numbers of underserved individuals there was also the need of equal rights for individuals with disabilities in China. Campbell and Uren (2011) examined the impact of traditional beliefs, Confucian ideology, Chinese government policy and the influences of the Western society on how China includes individuals with disabilities in the era of the 21st century. They used both the visual ethnography and an auto-ethnographic approach to examine the data. This data was collected over the course of five years and analyzed the impact of the Chinese government on disability policy, attitudes toward people with a disability, and how they are accommodated. They found that there have been positive outcomes from the efforts of the Chinese government in the areas of positive legislative and administrative policies, which assure equal rights for individuals with a disability. There has been a positive shift in attitudes toward individuals with a disability. Yet, from the stance of the community, this positive shift has had minimal impact on a larger scale. Individuals with a disability are still *invisible* in many public spaces (Campbell & Uren, 2011). Although these individuals may seem invisible to the society, they can start to become visible within their own homes. Chiang and Hadadian (2007) contributed to the literature of culture and disability by finding that Chinese-American, Chinese, and American parents of individuals with disabilities may need to be provided with parenting skills, information regarding the developmental disabilities, and a support system to alleviate some of the pressure of the challenges they face.

The type of services provided to an individual with a disability is determined by the cultural perspective of the disability (Eskay, Onu, Igbo, Obiyo, & Ugwuanyi, 2012). Prior to the colonial era the education system in Nigeria differed from that of the Western

society (Eskay et al., 2012). Since this was a construct derived from the Western society it did not hold any meaning in the society of Nigeria. Therefore, in Nigeria all students were educated together with the same instructional curriculum, including students with behavioral disorders, learning disabilities and typically developing students (Eskay et al., 2012). Yet, the society did treat individuals with a disability negatively. Although the students are included in the same class, there may be negative outcomes including incorrect assessment, inadequate services provided and individualized, and less parental involvement. For this study, culture will be viewed through a phenomenological perspective. The focus is on how one's culture makes meaning of their environment and the individuals within it.

Summary

In conclusion, this literature review explored the family structure and dynamics of having a child with a disability, focused on the sibling without the disability, and discussed how the disability is framed and interpreted culturally, socially and historically. Although being a sibling of an individual with a disability may bring challenges to a family structure, there are instances when siblings do adjust well and family cohesion is increased (Kaminsky & Dewey, 2002; Altiere & Kluge, 2009). There are varied reactions to individuals with a disability depending on the cultural lens through which the individual is viewed (Eskay et al., 2012; Campbell & Uren, 2011). Finally, being a sibling of an individual with a disability may foster resilience through the process and experiences of adversity (Walsh, 1998). The existing research regarding this topic is limited to the population of European American families (Sage & Jegatheesan, 2010). Therefore, this literature cannot be generalized to all families because it is not an accurate

representation of the families affected. Filling this literature gap would be a progression

for the field.

Chapter III

Methods

Introduction

The purpose of this study is to explore the experiences of siblings of persons with

disabilities. I am especially interested in not only the adverse siblings' experiences but

also their positive experiences. The purpose of Chapter III is to describe the methods

used in sufficient detail to meet Hays' and Singh's goal of dependability (2012). They

describe dependability as similar to reliability in that it pertains to the consistency of

study results over a period of time and across different researchers. As I discussed in

Chapter II, an extensive search of the literature found that the research has been limited to

European American families (Sage & Jegatheesan, 2010). Interviewing siblings of

individuals with disabilities from a heterogeneous sample will add significantly to the

literature on siblings of persons with disabilities.

Specifically, this research will address the following research questions:

1. How do individuals describe coping with the challenges of having a sibling
   with a disability?

2. How do individuals describe the benefits or advantages of having a sibling
   with a disability?

Theoretical Framework and Study Design

This qualitative study addresses these questions through a phenomenological

approach that utilizes Seidman's (1998) framework of in-depth interviews. Coherence is

the concept that there is consistency between the epistemological perspective and the

research design (Hays & Singh, 2012). This epistemological perspective and study design

is coherent. A phenomenological perspective is especially fitting with the in-depth

interviews because according to Moran (2000) and Dowling (2007), phenomenology is characterized as a philosophy that studies lived experiences and analyzes what these experiences consist of and the in-depth interviews in this study provide the opportunity for the participants to share their experiences. According to Seidman (1998), the purpose of in-depth interviewing is to learn both the subjective experiences of people and the meanings they create from those experiences. The meaning people make of their experiences leads to stories. These stories can then communicate the wisdom that people have acquired from experiences.

Furthermore, Seidman explains that the "primary way a researcher can investigate an educational organization, institution, or process is through the experience of the individual people, the 'others' who make up the organization or carry out the process" (Seidman, 1998, p. 4). He goes on to say that many studies focus on institutions, but not the perspectives and experiences of those within the institution. To learn about the experiences of others, one can do so by reviewing records, observing, experimenting, or questionnaires and surveys (Seidman, 1998). Yet, if the goal of the researcher is also to understand the meaning people make of their experiences, thus eliciting narratives or stories through interviews is fitting (Seidman, 1998).

Seidman recommends the use of a series of three interviews, each with its own focus. He argues that the advantages of a three-interview series is that it allows the interviewer the opportunity to gain a perspective of the context in which the interviewee's experience takes place, as opposed to conducting a one-time interview which may not provide enough context.

The goal of the first interview is to determine the context of the participants' experiences. This is done by asking the participants to discuss themselves as it relates to the focus of the study up until the present time. The second interview provides participants the opportunity to reconstruct their experiences in the context in which they occurred. The focus is on the present concrete details of the participants' experiences. The third interview aims to have participants reflect on the meaning attached to their experiences. This requires the participants to think of how their experiences have impacted their current life situation. Each interview should last 90 minutes and occur three days to one week apart. This space in time allows the participant to think about the preceding interview, but not too much time that the connection is lost between the interviews (Seidman, 1998).

There have been few studies that have allowed siblings of persons with disabilities to explore the meanings of their experiences. In addition, most research has focused on the adversity faced by siblings of persons with disabilities. My goal is to capture a more holistic picture of these lived experiences that includes challenges and benefits, as well as their experiences with school systems and in their families.

The Researcher

As a current school psychologist and a past developmental specialist and behavior interventionist, I work primarily with children that have been diagnosed with disabilities. Although I work directly with the individuals that have disabilities, I have become interested in their siblings' perspectives of the experiences of growing up with a sibling with a disability. My interest was initially piqued when I would work with the students in

the home setting as a developmental specialist and I would see their interactions with their brother and/or sister.

As I have continued to work in the field of special education there have been cases where the student with a disability is reportedly having an impact on their sibling(s). I was interested to know the type of impact they were having on their sibling and most importantly I wanted to know that information from the perspective of the siblings themselves. Much of the literature focuses on the parents' experiences, yet the siblings' experiences are not often detailed. Through the interview process, my objective was to capture the participants' thoughts regarding their experiences of having siblings with disabilities.

Participant Selection and Recruitment

I interviewed eight adult siblings of persons with disabilities. The inclusion criteria for the research study was that the participants be 18 years of age or older and have a sibling with a disability. I used purposeful sampling to recruit a heterogeneous group of participants. I define heterogeneity based on the following social categories: a) label of siblings' disabilities, b) racial and ethnic categories of the participant and their sibling, c) gender categories of the participant and their sibling, as well as d) the age of the participant in comparison to their sibling.

In an effort to maintain a heterogeneous sample it was important for me to keep these social categories in mind as I selected the participants. For example, I included siblings of individuals with varied disabilities from different self-identified racial and ethnic categories. It consists of a mixed group of siblings where some are brothers of sisters, brothers of brothers, and sisters of sisters. Also some participants are older than

their sibling with a disability while others are younger than their sibling with a disability.

To maintain confidentiality, alternative names have been used (See Table 4).

Table 4. Participant/Demographic Information						
	Siblings' Relation	Culture/ Ethnicity	Age (Older/ Younger)	Education	Profession	Siblings' Disability
Dan	Sister	Mexican-American/ Caucasian	29 (Younger)	Bachelor's Degree	Emergency Services Coordinator	Down Syndrome
Nora	Brother & Sister	Caucasian	29 (Younger)	Master's Degree	School Psychologist	Down Syndrome Intellectually Disabled
Fashia	Brother	African	31 (Older)	Doctorate Degree	Adjunct Professor	Autism
Drew	Brother	Caucasian	28 (Younger)	Some College	Asst Director (Disability Related)	Intellectually Disabled
Nicole	Brother	Caucasian	25 (Younger)	Bachelor's Degree	Speech and Language Pathology Asst.	Autism and Intellectually Disabled
Anabelle	Brother	Mexican-American	29 (Younger)	Cosme-tology Certifi-cation	Cosme-tologist	Learning Disability
Mae	Sister	African-American	63 (Older)	Some College	Mortgage Banking	Intellectually Disabled
Darius	Brother	Hispanic	33 (Older)	Some College	Supply Specialist	Down Syndrome

Initially, participants were recruited from a pool of persons already known to the

researcher. Some are colleagues and some are friends. Depending on the make-up of the

initial participants, further participants were recruited purposefully using a "snowball"

approach (Hays & Singh, 2012). As previously mentioned, one overarching goal of this

study is to give voice to the experiences of siblings. Recruiting the siblings from varied backgrounds with different stories to tell was a vital step in meeting this goal. I contacted participants by phone, e-mail, or in person to determine a meeting time and location and provided the participants with the Institutional Review Board (IRB)-approved consent form, either by e-mail before the first interview or at the time of the interview. Before the first interview, I reviewed the details of the study outlined in the consent form with the participants and answered any questions and addressed any concerns prior to obtaining their signature for consent. Upon receiving informed consent, the interviews were scheduled at times and locations convenient for the participants. There was not any form of compensation provided to the participants for their involvement in the study.

Data Collection

To answer the research questions, a broad interview protocol was followed during the interviews. I asked participants the following questions to gather demographic information:

1. What is your gender?

2. How do you identify yourself culturally or ethnically?

3. What is your age? Are you older or younger than your sibling?

4. What is your level of education?

5. What is your current profession or job?

6. Do you think your sibling influenced your career choice? If so, in what way?

Although the direction of the interviews may differ depending on the participants' experiences, each participant was asked to discuss the following topics:

Interview Protocol:

1. Tell me about yourself.

2. Tell me about your family.

   a. If they don't mention their sibling, ask a follow-up question regarding their sibling.

3. Tell me about your family's cultural practices.

   a. Did they differ from those of your extended family or community? If so, how?

   b. How did they influence your family's interaction with your sibling?

4. Tell me about you and your family's experiences with extended family members.

   a. How were they affected by your sibling?

   b. How did they influence your family's interaction with your sibling?

5. What challenges did your family face with your sibling?

   a. How did they cope with them?

6. Tell me about your family's experience with professionals and the school system around your sibling.

7. Tell me about the challenges you faced in your relationship with your sibling.

   a. Tell me about how you coped with these challenges.

8. Tell me about the benefits you gained from your relationship with your sibling.

9. Tell me how these challenges and benefits influence who you are today.

Trustworthiness

According to Hays and Singh (2012) there are several criteria for trustworthiness, some of which include confirmability, authenticity, and ethical validation. The level of

how much of the study's results genuinely reflects the participants being investigated while preventing interference from the researcher is confirmability (Hays & Singh, 2012). This is similar to authenticity where researchers try to discuss the participants' experiences and perspectives genuinely by presenting them accurately and in their original form. This study addresses the confirmability and authenticity criteria through member checking and memo writing. Member checking involves transcribing the verbal interviews into written text then sharing this text with the participant. This gives the participant the opportunity to confirm whether the interview text is a genuine reflection of their shared experiences. After each interview, the researcher wrote memos about the experiences the participant shared. The goal was to write about the participants' experiences and perspectives authentically. The memo writing helped with confirmability and authenticity by allowing the researcher to recap the information that had recently been shared. Since this was done soon after the interview, the details were more likely to be accurate. Ethical validation speaks to the idea of having ethical practices throughout all aspects of the research process.

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Establishing Categories and Themes

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After the in-depth interviews were transcribed, the data were organized and interpreted. Hays and Singh's (2012) 8-step qualitative data analysis was used.

Step1: Reduce Data -The first step involved deciding what was investigated, why it was investigated, and with whom it occurred. This was done in an effort to narrow the focus of analysis by limiting data analysis and data collection options. The data analysis was guided by the topic, research questions, research bias, conceptual

framework, access to participants and settings, and plans for establishing trustworthiness

(Hays & Singh, 2012). Once this step was complete, data collection began.

Step 2: Collect Data - As previously discussed, Seidman's (1998) three-step in-depth interviewing was used to collect data.

Step 3: Memo and Summarize - After each interview, the researcher completed a reflection memo. Writing reflection memos was an important step in the data collection process as it is usually the initial analysis that takes place with the new data (Hays & Singh, 2012). The reflection memo included information about the researcher's initial impressions of the interview, information that the interviewee provided that stood out to the researcher, and the researcher's thoughts about the flow of the interview process.

Step 4: Organize text - This step refers to transcribing the textual data. Each of the interviews were transcribed and provided to the participants for their review. The participants were given permission to change the transcription by deleting and/or editing their responses. As described above, this step is called "member checking." Member checking is defined as an "ongoing consultation with participants to test the 'goodness of fit' of developing findings as well as final reports" (Hays & Singh, 2012, p. 426). The participants agreed that the transcripts were accurate.

Additionally, in the interest of protecting the confidentiality of the participants, their names and their siblings' names were removed from the transcription and pseudonyms were used instead. The audio recordings and field notes were stored in a locked space to also maximize confidentiality. The participants were informed that all recordings would be destroyed upon completion of the study.

Step 5: Code - Hays and Singh (2012) define a code as "a label or tag that 'chunks' various amounts of data based on the defined case or unit of analysis." Other terms that may be used to describe a code include factor, item, theme, or subtheme. The identified codes in this study were either descriptive or interpretive and are explicitly described so that another researcher is able to identify the code for data based on the operational definition for it. Coding began before the data were collected. When the conceptual framework was developed, when the previous literature was reviewed, and the findings were analyzed, key phrases were noted and saved as possible codes. Next, once the text was organized it was considered in the context of the research purpose. This is when coding sources were determined. Examples of the coding sources include research questions, interview questions, conceptual framework, participant meanings, and nonverbal communication (Hays & Singh, 2012). Lastly, the decision to code written text by word, phrase, sentence, or paragraphs was made.

Step 6: Identify Themes and Patterns -To identify patterns it was necessary to examine the codes and identify ways in which the codes "chunk together" (Hays & Singh, 2012). Some factors that patterns emerged from include: frequency of omissions, similarity, co-occurrence of codes, triangulation and corroboration, and sequences of items or events (LeCompte & Schensul, 1999).

Step 7: Create a Codebook - Codes, subcodes, and patterns are listed in the codebook (Hays & Singh, 2012). It also includes a definition or description of each code and direct quotes from the data as examples for each code. The creation of the codebook started from the beginning of the coding process and was revised throughout the process of coding more data.

Step 8: Develop a Main Narrative or Theory - Lastly, the patterns identified across the varied data sources, the examination of how categories or concepts connect back to research questions, and how these categories or concepts relate to each other were all collectively brought together and articulated in a narrative form.

Presentation of Data

The next chapter discusses the findings of the study. The researcher has intentionally presented the data in a way that is unfiltered in an effort to preserve the voice of the siblings. Included are direct quotes of the experiences that siblings shared during the interviews. Using direct quotes gives the participants the opportunity to give their perspectives. After all, that is the purpose of this study: the commitment to give voice to siblings of individuals with disabilities by asking them to candidly share their experiences. The experiences that the siblings shared shape the findings section, which demonstrates the value of their voice (Corden & Sainsbury, 2006).

The purpose of using verbatim quotations was to use them as supporting evidence to show how themes emerged from the data. This allows readers to see the original data prior to the researcher's interpretations and analysis. Additionally, this strengthens credibility. The power of the participants' voices empowers them (Corden & Sainsbury, 2006).

Summary

This qualitative study addresses the gap in literature about siblings of persons with disabilities through a phenomenological framework. More specifically, interpretive phenomenology was the theoretical lens used for this study. The participants consisted of eight siblings of persons with disabilities. Participants were recruited from a pool of

persons already known to the researcher. The interviews were transcribed and provided to the participants for their review. After the in-depth interviews were transcribed, the data was organized and interpreted. Hays and Singh's (2012) 8-step qualitative data analysis was used.

Chapter IV

Findings

Introduction

This chapter will review the research questions, the population and information about the participants, outcome of the information that was gathered through the interviews, and the themes that emerged from the information.

This paper addressed the following research questions regarding the experiences of growing up with a brother and/or sister with a disability.

1. *How do individuals describe coping with the challenges of having a sibling with a disability?*

2. *How do individuals describe the benefits or advantages of having a sibling with a disability?*

To answer these questions, I interviewed eight siblings. A narrative describing their backgrounds is below. To maintain confidentiality, alternative names have been used.

Dan

Dan self-identifies as a Mexican-American and Caucasian male. He has a sister that has been diagnosed with Down Syndrome. He is younger than his sister and has earned a Bachelor's degree and works as an Emergency Services Coordinator.

Nora

Nora self identifies as a Caucasian female. She has a brother and a sister that have been diagnosed with Down Syndrome and an Intellectual Disability, respectively. Nora is older than both of her siblings and has earned a Master's degree and works as a School Psychologist.

Fashia

Fashia self identifies as an African female. She has a brother that has been diagnosed with autism. She is older than her brother and has earned a doctorate degree and works as an adjunct professor.

Drew

Drew self identifies as a White male. He has a brother that has been diagnosed with an intellectual disability. He is younger than his brother and has attended some college and works as an assistant director of a company that works with adults with disabilities.

Nicole

Nicole self identifies as a Caucasian female. She has a brother that has been diagnosed with autism and an intellectual disability. She is younger than her brother and has earned a bachelor's degree and works as a speech and language pathologist assistant.

Annabelle

Annabelle self identifies as a Mexican-American female. She has a brother that has been diagnosed with a learning disability. She is younger than her brother and has earned a cosmetology certification and works as a cosmetologist.

Mae

Mae self identifies as an Afro-American female. She has a sister that has been diagnosed with an intellectual disability. She is older than her sister and has attended some college and worked as a mortgage banker.

Darius

Darius self identifies as a Hispanic male. He has a brother that has been diagnosed with Down syndrome. He is older that his brother and has attended some college and works as a supply specialist.

Each of them was interviewed three times for a total of 24 interviews. In all but four cases the three interviews were conducted 4-7 days apart. Three interviewees were interviewed eight days apart for one of their interviews and one of the interviewees was interviewed 14 days apart for one of the interviews. Each of the interviews lasted approximately 60 to 90 minutes. The participants were either already known by the researcher or referred by someone that knows the researcher. The participants ranged in age from mid-twenties to mid-sixties. Participants were from a diverse group of ethnicities: African-American, Caucasian, Mexican-American, and bi-racial with varied educational backgrounds ranging from high school to college graduates. Of the eight siblings interviewed, three of them currently live with their siblings that have disabilities. The siblings with disabilities ranged in age from low-twenties to mid-fifties. Their diagnoses included autism, Down syndrome, learning disability and intellectual disability.

Based on the information gathered, the data uncovered themes related to challenges, coping, and benefits. Within the challenges section the underlying themes include: (a) the challenge of learning about being different from their sibling, (b) the family's struggle to advocate for the services provided for the sibling, (c) creating an environment that accommodates their siblings' needs, and (d) the siblings' willingness to be the designated individual to carry out the responsibilities for their siblings' long-term

care. The coping section details the following themes: (a) the need for siblings to seek community and social support, (b) the parentification of siblings, and (c) extended family members' adjustment to the differences of individuals with disabilities and normalizing them. Lastly, the benefits section includes the following themes: (a) character qualities the siblings have acquired as a result of their experiences and (b) the influence of having a sibling with a disability on career choice

Throughout this chapter I will review these themes alongside the stories shared by the eight siblings.

Challenges

Physicians and Diagnosis: The Challenge of Learning about Being Different from their Sibling

During the interviews, each of the siblings discussed interactions with physicians and learning of their sibling's diagnosis. Some of the siblings expressed how their siblings' disabilities made them feel different from their siblings. The first theme that emerged is the challenge of learning about being different from their sibling.

Nora discussed how she connected her sister's diagnosis to her father's exposure to Agent Orange and diagnosis of PTSD:

> I think it's because my dad was in Vietnam and he was exposed to Agent Orange and he had a diagnosis of PTSD and so he was stressed. I know that when you're overly stressed, it can affect your sperm, or even just the exposure to Agent Orange, exposure to all the chemical warfare...My mom didn't know until she was almost two. She started getting a rash on her body and then she start having seizures and then they did all these tests. You can see her disease under a blue

lamp. Her whole body will light up white, with all these white patches underneath it.

Nora also discussed how as they grew older, the differences between her and her sibling became more noticeable:

She knew what was up that I was able to do things faster and better and quicker. I was able to do a lot of things with friends and I had lot more independence than she did and I was a lot younger. When my sister realized that I got a driver's license, she was really upset and I think it like hurt her feelings and just realized 'I have disabilities.' She has even said it, I understand I have a disability. I'm not like Michael but I know I'm not like Nora. She said that. I've heard her say that early in college, undergrad. I was like, okay. She does realize it, which was kind of sad.

Mae discussed her experience of learning that her sister is different from her:

In this house back in those days, a lot of African American people weren't exposed to different diagnosis and sicknesses and how it had to be treated. We just had to see as we got older and her being a sibling we just started noticing that her capabilities wasn't what we were doing. She couldn't learn to do math or all that stuff.

The similarity within these responses is that each of the siblings knew that their brother and/or sister were different from them.

Navigating the Education System: The Family's Struggle to Advocate for the Services Provided for the Sibling

This section focuses on how the families with children that have disabilities navigate school systems. As shown in the data, some of the siblings described how their brothers and sisters had teachers that were supportive and interacted well with them. On the other hand, other siblings found the school systems unhelpful and insensitive. Some of the siblings discussed their involvement with the Individualized Education Program (IEP) meetings and discussed their school program. The theme that surfaced is the family's struggle to advocate for the services provided for the sibling. Fashia discussed how her family was satisfied with the services that her brother's school was providing. She later did express her dissatisfaction with the adult transition program he was receiving services from:

> Since he had had the right diagnosis and the school put in extra services, his language has developed a lot. He had very good ... His social service worker, she was really good. My mom had a really good relationship with her...It was just he got really aggressive so they felt as if it would be better to be in a smaller environment, whatever the case may be. I think they also recognized that what they were doing weren't helping him to progress enough.

Drew also expressed his satisfaction with the services his brother is receiving from his program:

> If he's going to program, it's structured. They'll have a schedule and all that kind of stuff. I think for his, I think it's a little bit different in the sense that they have more of a classroom setting and they tend to do more classroom type stuff where

they're doing reading or they're working out there or they're doing that kind of

stuff to help them out. For Ben, because he has so many behaviors, he's not

appropriate to be out in the community. He can't be in a community-based

program. He has to be in a behavioral mod program where they're not always in

the community but they do go out in the community sometimes. They do have a

behavioral specialist that comes there and makes a program for him, like it's

designed for him and the plan of tactics and all of that kind of stuff. They

definitely do have all the data and stuff. They'll give him all the goals that he

needs to be working from a day to day basis.

Nicole also echoed the notion of satisfaction with her brother's current program:

Yeah, and then they bus him to a place called Adult Care, which is an after-

school program for more of ... They do children but his group is adults and

adolescents with disabilities. Really good program; they do a lot of community-

based outings and things like that. He goes there every day for about two to two

and half hours. Then school's not really school anymore its more community

stuff, yeah, and they do job training every other day. No academics, really; they

pretty much moved away from that.

Nora discusses her mother's frustration regarding the lack of services her brother and

sister were receiving. The need to advocate for more was expressed:

I just remember my mom finding it to be a big struggle for her. She was

complaining all the time of the teachers, how the teachers … Especially when my

brother and sister were younger how she didn't like any of the teachers. She

thought they were mean. She didn't think that they were very genuine or cared

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really about Michael or Rachel. I remember her feeling frustrated that she wasn't

getting services and support that she wanted to get for them.

Nicole also expresses how she has needed to advocate for her brother:

Now that he's been older I've only attended his IEPs for the past three years. I

always attend with my mom now since I got more interested in ABA and speech,

I feel like, "Oh, I can go; I can help you." I feel like the staff has been pretty

good- Yeah, but with certain ... I feel like the service providers, like the OT and

the speech, maybe could be better. Just because I feel like they don't set very high

expectations... The goals that they've written for him have been pretty low, I feel

like. It's been hard to fight for things in that sense and my mom, I think, the older

my brother gets the more lax she gets with that stuff and I think she has become

one of those parents that just listens and says, okay, and signs it. Which sounds

bad that I'm judging her that way, but I think maybe her expectations aren't so

high anymore because he is older... I've had to try and speak up at times- Yeah,

and ask why things were written the way they were or if we could tweak it, could

be a little more of a challenge, you know? A lot of his stuff is really functional at

this point anyway, but I feel like I, on this side of it where I'm the sibling, versus

just observing or a service provider, I feel like you really do have to fight for

more.

The common thread among the siblings' experiences with the education system is

that they shared the need to advocate for their brother and/or sister. This may entail

additional services to enhance their siblings' education experience or even finding a good

match between their siblings' needs and the educational facility they are receiving

services from. The need to advocate for this has been expressed from many of the siblings.

Siblings' Behaviors: Creating an Environment That Accommodates their Siblings' Needs

Some of the siblings shared that their brothers' and sisters' behaviors are challenging to handle. They detailed the impact that these behaviors have on the family. The fourth theme that emerged is creating an environment that accommodates their siblings' needs.

Fashia discussed her brother's challenging behaviors and how she responded to them:

Then we went through the phase where he would... He liked chewing on

socks. Which was terrible, because... My older brother, of course, was messy. So

my parents were like, you have to hide the socks. It's not even chew on them, he

liked playing with them. So he would steal people's socks. Yeah. But we went

through that.

Drew explained how he would try to stop his brother's behaviors from escalating:

Patience; patience, patience, patience. That was a gigantic challenge because he

would have behavior daily of attacking one of us or yelling at us, screaming at the

top of his lungs. He would turn into a Power Ranger because he would speak the

language that all Power Rangers speak. We would have to turn into all the Power

Rangers united and created that big guy. We would always have to trick him. We

would always have to turn yourself to be one of those. We were the bigger Power

Ranger and he would settle down. That was a really, really big struggle that we

had.

Nicole expressed the challenge of anticipating when her brother's behaviors would occur:

I think he probably started showing early signs of it and that was just frustrating

because he would have an episode or have a meltdown or a tantrum just

randomly. You never really quite knew when it was going to happen and usually

it was if we went to a restaurant or something, it could have been at the grocery

store. Just being aware of things that would trigger a tantrum for him and that was

the biggest thing. It's frustrating and it was embarrassing because we could be at a

restaurant and he would just flip out and we would have to leave. We would just

be like box up the food we got to go.

Each of the siblings shared that their brother/and or sister would engage in

challenging behaviors. Therefore, the families found ways to accommodate their siblings'

environments whether it was to hide socks, to turn into a Power Ranger or box up the

food at a restaurant. Their environment was altered to accommodate their varied needs.

Long-Term Care: Being the Designated Individual to Carry Out the Responsibilities

for Their Siblings' Long-Term Care.

Worrying about their siblings' future is another challenge that they discussed. The

next theme is being the designated individual to carry out the responsibilities for their

sibling's long-term care. Below are some of the experiences that they shared.

Fashia discussed how her brother's living arrangements would most likely be in

the future:

She [Fashia's mother] was concerned about when her and my dad die, what's going to happen to him [Fashia's brother]. My thing is I already know that that's my responsibility. I wouldn't send my brother to a home because he's very, he's so special and you have to know him or else, yes. I told her that that's one of the things that when I meet a guy that I think will be my husband, I'm going to make it very clear and up front that I'm going to take care of my younger brother for the rest of my life, so it's like a two-package deal with my younger brother. When my younger brother gets a certain age, he's going to live in Ghana. I think once my parents go back, he's going to go back with them. Then he's going to live in Ghana with my older brother, because it's easier that way because then we have relatives there and they can watch him and help my brother. Yeah. Then we'll probably send him back to the US for a few months to be with me and then go back there.

Mae shared that she has been taking care of her sister for several years:

I think I'm an adjuster and I can keep evolving and going on because working with the developmentally disabled adults was one thing but I have to go home to every day and Barbara's been with me most of her life because our mom wasn't able to take care of us. At the age of 14 or 15, I thought she was just a parent that's just like a lot of the other parents around us – didn't care and off partying and doing her thing. She was developmentally delayed.

Nora explained her impression of taking on the responsibility of providing long-term care:

When I was younger, I'm more mature now, but it used to be like, "Okay, if

anything happens to my mom or dad, Michael and Rachel are my responsibility."

I learned that from high school. Before I was kind of upset, I was a little annoyed

about it. Before I was aware of how well my sister would do living independently,

but I always just thought 'Man, I'm going to have to explain to my husband that

my siblings are going to be moving in with us because they can't live

independently.' Whoever obviously would want to marry me would have to have

been okay with that. But that changed as I grew up and got older. Also changed

when I started working for the state, the Department of Developmental Services. I

was way more aware of all the support that the state provides to people

with disabilities, and how my sister's totally happy in a group home.

The siblings express their worries to take on the responsibility of their brothers'

and sisters' long-term care. Yet, they indicate that they are willing to take care of them.

As discussed, the common challenges that the siblings expressed during the

interviews were learning that their brother and/or sister is different from them based on

their diagnosis, navigating the education system to advocate for their siblings' services,

and worrying about the long-term care for their siblings.

Coping

Social Outlets: The Need for Siblings to Seek Some Type of Community Activities

and Social Support

Many of the siblings share ways that they cope with the challenges of having a

sibling with a disability. The common theme amongst these coping strategies is that the

siblings seek some type of community activities and social support.

Nora explained that she has become more involved in non-profit organizations:

If I were to have a coping way, I think I'm just more proactive. I try to give more to nonprofits and do more things. I just want to make sure, like be as involved as I can in organizations that do a lot for people with disabilities because I don't think that they're … I think that one of the struggles my mom had and maybe why I am the way that I am too is there weren't always that many opportunities for them to do a lot of things. It's limited in a sense. Just thinking outside the box and working with other people and doing movie nights and karaoke nights and just trying to be more involved and help in that sense.

Nicole discussed how yoga has helped her cope:

I do a lot of yoga. Yeah, and I try to use ... I've read books and I try to use the whole philosophy of yoga in my everyday life, just to keep me sane, you know? I try to do it on my own, at least a little bit every day. Even if it was just like some simple stretching and quiet time. I think that my parents aren't so into things like that so I discovered that on my own and it works for me, so I've stuck with it for at least a few years now.

Mae stated that one of her other sisters helps with her sister that has a disability. She expressed that she would take time to be with friends when she needed to:

I have a group of good friends. I do horseback riding and I go to horse shows. I'm in the food service for the United States of Olympic Horses. I do those big shows 3 times a year. You have to find … I have worked and arranged it with my sister in San Diego to give me … 'You have to give me a break.' She'll keep her when I go on the road to do my horse shows. I can try to get her to take her one weekend a month.

The commonality that these examples point to is that the siblings look to settings and activities to become involved with that allow them time away from their brother and/or sister. This provides the opportunity for them to focus on themselves by engaging in activities they enjoy such as playing sports, spending time with their friends, being involved in nonprofit organizations and yoga.

Parentification: Siblings Being Put in a Position to Assume the Role of Instrumental Parentification

"Instrumental Parentification" is a term used to describe the siblings' participation in the physical maintenance of the family (Hooper, 2008). Completing daily tasks that include caring for siblings are considered instrumental parentification. During the interviews a theme surfaced regarding siblings being put in a position to assume the role of parentification. Instrumental Parentification specifically is when the child completes tasks for the family such as caring for their siblings. Furthermore, these acts of "required helpfulness" (Rachman, 1979) are viewed as ways the siblings find themselves to be making a contribution to the family in response to social requirements. The siblings see this as a way of coping and a protective factor in a sense. These experiences are discussed below.

Fashia explained her perception of assuming a parental role:

Even though it's not my child, I have that same... I take it upon myself to have that responsibility. Yeah, I mean... I'll wholeheartedly admit that I make the choice to help my parents care for my brother. It's not like I... I don't have to. But I make the choice to do so. Yeah, it's like, I mean, a part of it is like he's my son, and the other part is like, he's my brother...Actually, the week before, the Friday

before I was leaving for college, or the week before, I helped my parents get

my younger brother ready for school over the summer. He goes to summer

school. So as I'm helping them, my mom of course breaks down crying, because

she's like, you do so much, you help us so much. You know, like, I don't know

how it's going to be, thank you so much, and all this stuff. And then of course, I'm

in tears, because I'm like, no, nobody's going to be able to do it. So that was hard,

and then actually leaving was like... Really hard. Yeah, but a part of me knew

that, like, it's okay, you know what I mean? It's okay, and it's truly my parents'

responsibility.

Mae described her experience with parentification:

My grandmother passed away. Our job was to take care of her. That was the

thing, 'Take care of that little girl when you're out there. Make sure she isn't

doing something crazy. Our job was to make sure that she didn't wind up … Get

in trouble or go off with a stranger. That was our job. Everybody took care of

their own.

Nora shared that she also assumed a parental role for her siblings:

"He was the oldest brother, even though I had my responsibilities. I was the oldest

child in the sense, like I took care of everyone, well my siblings."

Several other siblings discussed how they have taken on the role of their parent(s)

as it relates to caring for their brother and/or sister. Many of them discussed how they

would look after their sibling while their parent(s) were at work. They even expressed

that they cared and worried for their siblings as if they were their own children.

Interactions with Extended Family Members: Extended Family Members'

Adjustment to the Differences of Individuals with Disabilities and Normalizing

Them

The siblings discussed how their extended family members perceived and interacted with their brothers and sisters. The theme that emerged from this conversation is that the family members adjusted to their differences and began normalizing them. Many of them explained that the extended family members interacted with their sibling the same way they interacted with them.

Fashia explained how her family interacts with her brother:

I think because of the way we treated him, it was like a model to them actually with how to treat him. They learned to do the same. It's still considered that he's autistic and can't do everything, but they know when he's being lazy and don't just anticipate what he can do.

Nora discussed her family's involvement with her siblings:

My aunt and cousins are pretty involved. We spent all of our holidays with them. When we were in high school and my siblings were more in sports, they would come and support them at Special Olympics. My siblings really enjoyed going over to their house and we'd spend the night. We do that. My mom's brother and my dad's sister, they live far away so we would see them on holidays. Then, grandparents were involved at Special Olympics until they passed away.

Nicole expressed that her family makes an effort to get to know her brother:

Our Uncle Mark and Aunt Sally are very close to him and they're probably ... We

have a very large family, but they're like the ones that have really taken the time

to understand Daniel and to know him. He enjoys being around them because

they totally spoil him. They just do whatever he wants to do and he's just always

happy, so he will request to see them.

The commonalities amid the perceptions of extended family members include

how the siblings expressed that the extended family members interacted with their

siblings the same way as them and they discussed the involvement of their extended

family in their siblings' life.

<div align="center">**Benefits**</div>

**Character Qualities: Character Qualities the Siblings Have Acquired as a Result of
Their Experiences**

The siblings were asked about their experiences with their brothers and sisters and

many of them discussed the perceived benefits of having a sibling with a disability. The

next theme is that several of the participants discussed the impact their sibling has on

them which has led to the character qualities they have acquired as a result of these

experiences.

Fashia said that although having a sibling with autism was challenging, it also

helped her become more understanding of others:

Oh. It's been fun. I think it's hard. It's very challenging, but through the challenge

it changes you. I know even like my older brother, my dad, it really has changed

us. I know, for me, I'm very empathetic and caring of others because I have

someone who depends on me. I don't know. At first, it was sometimes like a

burden when I was younger, but I appreciate having a younger brother with autism. Yeah. It's like God's greatest blessing. I think it opened my mind to understanding human behavior and it gave me that empathy I needed to work with others...I mean, I think it really impacted the person that I am. I think that's the biggest part, is it impacted my personality and character.

Drew discussed how his experiences with his sibling helped him become a more patient person:

I don't think I'd be as patient if I didn't have Ben because I have behavioral problems myself. Yeah. I definitely think he helped me with having a little bit more patience in life and I think he helped me be a happier person. It puts life in this perspective for you...I think we have a softer heart for people. We have an understanding of disabilities and of people, how they react to certain things.

Nora explained how she also has become a more understanding and open person:

I think it's made me a more understanding person. I think how I treat and approach other people is different from some of my friends who don't have … helps me I think in my job, working with people. When I was younger, I didn't know anything else. It was what it was... I think that how I am today is because of my experiences with my brother and sister is just being a lot more accepting of all individuals and always trying to keep an open perspective of what … Rather than just the appearance of what's going on that there could be challenges, cognitively, emotionally that we may not know and be aware of. Trying to be more of an open thinker and just really accepting of others, I think. I hope.

The theme of acquiring positive character qualities was expressed throughout the discussions. The participants gave credit to their siblings for being the reason for the development of these characteristics.

Career Choice: The Influence of Career Choices by the Individuals with Disabilities

The final theme is that the participants describe how their life choices such as their profession have been influenced by their brothers and sisters. Many of them expressed that they felt more equipped to work with individuals with disabilities as a result of their experiences with their siblings.

Nora discussed the nonprofit organization for persons with developmental disabilities she recently started:

> Recently, I started a nonprofit with some friends, with friends who are siblings of those who have developmental disabilities or challenges. We've been working on that for a while. We just got approved. We're in the stages of still formalizing what we really want to do, but we do have a big sibling component. We're more of a volunteer base now where we just recruited a lot of our friends. We help out other nonprofits find volunteers for any event. I've held board memberships with other nonprofits and that was definitely influenced by my siblings and my participation with them.

Drew explained how his brother made an impact on his and his other siblings' career paths:

> Ben, if anything, helped everybody in the long run and in the short term, too, because he definitely did bring a lot of perspective to us. Molly, I think that might have helped her career path. Yeah, because Molly went the whole

psychology route, and I can definitely see how that might have helped Molly go

that route. Mike also worked in this industry for a long time as well.

Nicole discussed her experiences in the field:

I think that, obviously, it led me to the career that I want to be in, but I think it's

given me a natural ability to just to relate individuals with disabilities across the

board, and not just autism. I think that I just ... I feel like I have an understanding

with them and they're comfortable with me and I naturally just have good

relationships with them. They feel comfortable; it's almost like they just know you

get it, even if I'm working with them as a SLPA, or an ABA therapist or

something; I just felt like I had less problems with kids. I don't know; it's probably

affected the way that I handle stress and patience and things like that just because

I'm so used to things being the way they are at our house...I feel like it's affected

just the way I can relate to those individuals more than picking up ... I think I

probably picked up therapy quicker because of my experiences. I didn't struggle

with working with kids ever; it was just natural. It's affected all aspects of my

jobs; different jobs, yeah.

The detailed experiences of having a sibling with disabilities makes an impact on

career choice. These siblings really want to see a positive difference in the lives of other

individuals with disabilities and they find the best way to make this difference is to join

others that work in different capacities of this field.

Summary

The analysis of the data uncovered three main sections including challenges,

coping, and benefits. Within the challenges section the underlying themes include: (a) the

challenge of learning about being different from their sibling, (b) the family's satisfaction with services provided and the need to advocate for the sibling, (c) creating an environment that decreases the likelihood for their siblings' behaviors to occur, and (d) being the designated individual to carry out the responsibilities for their siblings' long-term care. The coping section details the following themes: (a) the need for siblings to seek some type of community activities and social support, (b) siblings being put in a position to assume the role of parentification, and (c) extended family members' adjustment to the differences of individuals with disabilities and normalizing them. Lastly, the benefits section includes the following themes (a) the impact their sibling has on them which has led to the character qualities they have acquired as a result of these experiences and (b) the influence of career choices by the individuals with disabilities. Each of these findings has been reviewed. Direct quotes from the participants' interviews have also been discussed. The next chapter will discuss the limitations of these findings and directly answer each of the research questions.

Chapter V

Discussion

Introduction

The purpose of this chapter is to directly answer each of the research questions that were posed at the beginning of this study. The aforementioned themes will be referenced as the questions are answered and so will the previously discussed literature from past research studies. It is important to consider the emergent themes as it relates to answering the research questions because those findings are in essence the answers.

Research Question #1

The first research question is:

1. How do individuals describe coping with the challenges of having a sibling with a disability?

During the interviews, the siblings expressed how they cope with the challenges of having a sibling with a disability. The siblings stated that they found interest in activities outside of the household away from their brothers and sisters. Some of these interests/activities include fashion, shopping, playing sports, spending time with friends, and yoga. A couple of the siblings expressed that they cope by starting a nonprofit organization in their siblings' honor. The organization puts on activities for the community in support of individuals with disabilities and their families. The emergent theme found among the activities that they engage in to cope was the sense of community and social support. Maximizing social networks and supports is one of the four ways that Sheridan, Sjuts, and Coutts (2012) described to promote resilience among families in the literature previously discussed.

As discussed in the previously reviewed literature, Walsh (1998) defined resilience in part as "… the capacity to rebound from adversity strengthened and more resourceful… The ability to overcome the blows of outrageous fortune challenges …" These siblings explained their experiences of how they rebounded from what can be described as adversarial circumstances growing up with siblings that have disabilities. They talked about how they were strengthened and overcame these challenges. Additionally, the topics of volunteering (Marks, Matson, & Barraza, 2005), perception of social support (Altiere & Kluge, 2009), and measuring the effects of coping on the well-being of parents (Pottie & Ingram, 2008) was discussed. The latter two studies were in reference to the parents' experiences and now that can be compared to the experiences the siblings shared in this study. Marks, Matson, and Barraza (2005) concluded that siblings of individuals with disabilities gained experience volunteering by helping with activities that were being put on for the individuals with disabilities. That is similar to the siblings in this study that shared their experiences of volunteering to start a nonprofit organization for individuals with disabilities and their families. The findings of Altiere and Kluge (2009) indicated that the parents had an accurate perception of the social support they received. As in this study, the siblings are aware of the social support they receive from their friends, family, and the community. The study from Pottie and Ingram (2008) used a measurement to measure the effects of coping on the well-being of parents of individuals with disabilities. It would be a great comparison if a future study administered the same measure with siblings of individuals with disabilities.

Research Question #2:

The second research question is:

2. How do individuals describe the benefits or advantages of having a sibling with a disability?

Throughout the conversations the siblings shared the benefits or advantages of having a sibling with a disability. Several of them discussed positive character qualities and personality traits they have acquired as a result of these experiences. Some of those qualities include increased patience, being empathetic and caring of others, developing a greater understanding of others without judgment, being more conscious of others' abilities, and being more of an open thinker. Furthermore, most of the siblings expressed that their brothers and sisters actually brought their families closer together and increased cohesion. Additionally, they describe how life choices such as their profession have been influenced by their brothers and sisters. They share that they are more comfortable working with people with disabilities than others may be. They find themselves to be more driven, motivated and willing to help others. The theme identified among the siblings' responses with regard to the benefits or advantages of having a sibling with a disability is the notion of seeing their brothers and sisters in a positive light.

There have been few studies that have allowed siblings of persons with disabilities to explore the meanings of their experiences. Most research has focused on the adversity faced by siblings of persons with disabilities rather than to capture a more holistic picture of these lived experiences by including the perceived benefits. In this study the following challenges were discussed by the siblings: (a) the challenge of learning about being different from their sibling, (b) the family's struggle to advocate for

the services provided for the sibling, (c) creating an environment that accommodates their siblings' needs, and (d) the siblings' willingness to be the designated individual to carry out the responsibilities for their siblings' long-term care. Yet, the aforementioned benefits or advantages of having a sibling with a disability were also discussed in an effort to capture a more holistic picture. As outlined in the literature review, Kaminsky and Dewey (2001) found that siblings of individuals with disabilities tend to admire their siblings more than individuals without disabilities. Through the responses given from the siblings in this study, it is clear that they have an admiration for their siblings and their lives are positively influenced because of it. The literature also discussed how the siblings without disabilities have strengthened psychosocial and emotional development as a result of their experiences of growing up with siblings with disabilities (Macks and Reeve, 2007). That is the general consensus of the experiences shared in this study as well. Macks and Reeve (2007) also noted that families with individuals with disabilities are more cohesive and the siblings of this study also speak to that as they express that their families increased cohesion is a result of the experiences with their siblings.

Strengths and Limitations

The strengths of this study are that ultimately the voices of siblings of individuals with disabilities were heard. Their experiences have been shared in a more holistic view in this study in comparison to studies that focus on the challenges of having a sibling with a disability. Furthermore, siblings from varied backgrounds were included in the study which encompasses a diversified demographic as opposed to only those of the Caucasian demographic. The findings of this study are important because they are one of the first

contributions to the literature that begins to fill the gap for siblings that have shared a holistic perspective of having a sibling with a disability from varied backgrounds.

This study has a couple of limitations. One of the limitations is that this study only involved eight siblings. Therefore, the findings of this study cannot be generalized to all siblings of individuals with disabilities. Secondly, this study focused on siblings of individuals with a variety of disabilities regardless of their severity. Possibly results would have been different if this study focused only on mild disabilities or only severe disabilities. With that said, it is important to not generalize these siblings' experiences to other siblings of individuals with disabilities.

Summary

The purpose of this chapter was to directly answer each of the research questions that were posed at the beginning of this study. The previously discussed themes were referenced as the research questions were answered. The previously discussed literature from past research studies was also reviewed. The answers to the research question regarding coping detailed the following themes: (a) the need for siblings to seek some type of community activities and social support, (b) siblings being put in a position to assume the role of parentification, and (c) extended family members' adjustment to the differences of individuals with disabilities and normalizing them. The answers to the research question regarding benefits included the following themes (a) the impact their sibling has on them which has led to the character qualities they have acquired as a result of these experiences and (b) the influence of career choices by the individuals with disabilities. Each of these findings has been reviewed and is a contribution to the research about siblings of individuals with disabilities. This study has given siblings a voice to

share their lived experiences. The incorporation of the shared benefits and advantages of having a sibling with a disability make the findings of this study unique and is also the most important take away from this research.

Chapter VI

Messages

Introduction

Conducting this study has given siblings of individuals with disabilities a voice to share their experiences. Their voices collectively are sending messages to families, educators, professionals and future researchers. In addition, they shared advice they have for other siblings that have brothers and sisters with disabilities. This chapter covers the study's implications in the form of messages to different audiences.

Messages for Families

The message they are sending to families is that it is okay to accept their sibling for who they are. Although there may be several challenges, their sibling has taught them to be more caring, patient, loving and kind. The siblings share their thoughts.

Nora shared:

> If I could go back and do anything differently, I think that, I wish that I was more of an advocate for them [siblings] to be more independent. Even stand up to my parents a little bit more, 'cause I think my parents were helicopter parents and overprotected them from life and from things. I think that if I could go back, that would be the one thing that I would do. Help my parents not be so overbearing. Letting them make decisions. I think my parents kind of got into this routine where it's easier to make the decisions for them because it was faster and easy. Just being confident in myself and older, and more aware of their abilities to say 'I think that they got it. Give them a chance. It takes them longer to do things, but

that's fine.' To have more patience. That would be the one thing that I would change.

Nicole shared:

My mom, I think, takes on a lot and my dad, he goes to work and he provides but my mom also goes to work and then she takes on all these other things. I think that I've always been hard on my dad, I think because of that. I don't, obviously, I don't understand quite what it's like to be the father in this situation, and have to work full time, and come home to that, but I think he and I tend to butt heads. Because I will want to voice my opinion, but ... Sometimes I will, even if I know it's not going to go well. I'm an adult now, and he's still, I think, tries to treat me like a, well, I am his child, but I'm not a child. I think- He tries to treat me like I can't have an opinion about- him, or our situation, or parenting, things like that. Whereas, I disagree because I'm an adult and if I have to live there then it affects me, and he has always- he's always denied that it affects me just because I'm the child. I think it's really affected our relationship because I feel like he doesn't treat me like I'm affected by any of it. I think that I'm absolutely just as much affected as they are. Right, and yeah, I was a sibling of him, or I am a sibling of him, but that's all I knew growing up. Whereas, he had a normal upbringing with five typical siblings and this happened later in life with his child, so it's totally different. We have totally different experiences of you know.

Mae shared:

Society doesn't do that anymore. Children get put away. Children are getting emancipated now. People need to get more involved and go back to family

structure. We need to take care of our own as our government can't take care of them because they don't know them, they don't love them.

Darius shared:

When he does anything, he takes his precious time and we don't mind but he showed us like at first we were like, 'Well hurry up.' Even when it comes to eating but he takes his time and we're like, You know what, let him enjoy his food.' ... I guess he made us to have a soft heart in that area which I think is a great thing.

Messages for Educators

The message they are sending to educators is that they would like their sibling to be treated with love and care and to receive the appropriate educational services they are supposed to receive without having to put up a fight to receive them. The siblings share their experiences.

Fashia shared:

In Ghana, they don't have full educational schools for children with autism. Literally I think it's like there's not that many schools out there. It's really hard to find a school for them. Some people end up just keeping them at home. Other people do ... If they can get them into the school, they send them to the school, but there's not that many.

Darius shared:

She started getting along with the teachers more even though she barely speaks English. She could communicate with them. She would go with them to all the field trips and then we would be like, 'Okay, where are you going now, mom?'

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'I'm going to go with Jessie to this and then to here.' Like, it [experience of his brother going to school] was different, because we had the school bus picking him up, a yellow one, and we seen the other kids in there, like in there first, you know it was like, I mean seeing him growing up a couple of years, already 4 or 5, and seeing the other kids, it's like ... I used to tell my mom, 'Scott's not like that.' She's like, 'I know, but he's not where, he's more advanced than them, but he's not where the regular students are right now.' It was kind of different, because we would see children who were like in wheelchairs or making a lot of noise, and a little bit more advanced on that stuff...He's not better than anybody else, but I just felt he was more advanced on certain areas than other children. It was hard to, like see them. I was like, in my mind, 'Okay, he shouldn't be in the class with them, like he's not that way,' but it humbled me, because I started going to his back-to-schools and everything. It was good, too, like the kids would come up to me, and it's like, 'Are you Darius, Scott's brother? He always talks about you.' Even his teachers, so it was warming and humble. I started learning their names, and then they were like, when I would take him to the bus, because I would go late sometimes to work, and they would want to high five me through the window and everything, so it was like, okay.

Messages for Professionals

The message they are sending to professionals is that taking the time to determine the accurate diagnosis for their sibling's disability is very important because it impacts the services that their sibling receives. They also want the professionals to know that they

don't always see their siblings' disabilities as a burden. The siblings discuss their

thoughts.

Darius shared:

> Benefits is having patience, having calmness, being able to cope with the whole
>
> thing like it's just like not seen as a challenge but seen as a blessing. Being able to
>
> help a child grow and grow and even though he's going slow but seeing him grow
>
> in certain areas, seeing him ... I guess even looking at pictures like a couple of
>
> years ago to how he is now and how he's acting, how he responds to things, things
>
> went sure along. It's like a blessing to see him grow. To me, it's like a flower that
>
> would always keep growing in that area I think. I guess it's not going to stop and I
>
> don't mind. Even if it's slow. That's the whole thing of me. That's why I want to
>
> push to make sure that all the documents are signed because I wouldn't want him
>
> to go anywhere else. I wouldn't want him to go to ... He's nobody's burden. He's
>
> my brother. I'm going to take care of him...You know, he was born, and we
>
> started seeing other things, where they told us he was born with an extra
>
> chromosome, so he had Down syndrome. You know, you can tell a little bit more,
>
> but it didn't stop us from loving him. I guess, you can say I adapted to that pretty
>
> fast. It was different, a lot different, but it didn't change the way we looked at him.
>
> I think they [physicians] had told her [mother] that there was going to be a chance
>
> [that his brother would have Down syndrome], and then as it got closer, they had
>
> told her that she was, but that didn't stop her. She was like, even when he was
>
> born, she was like, and when she finally told us, she was like, 'He's still my son.
>
> He's still your brother. It's going to be a little challenging, maybe not, but all we

can do is love on him and, you know help him.'...At the beginning, I wouldn't

even know how to react with, because all we knew is we had another baby brother

and we already knew he was going to come out with an extra chromosome, Down

syndrome, but then again, didn't really know what to expect. We're just, I mean,

from our perspective, we just had another baby brother and we were just going to

go with it and go from there. We weren't going to treat him any different. We

didn't even know if he was going to be I guess advanced or not advanced, or

anything. This was our first time we were ever dealing with a child or a brother, a

family relative that close to us where we were gonna see what is to come of it.

Messages for Future Researchers

The messages they are sending to future researchers is to continue to explore the

experiences of siblings of individuals with disabilities. Many of the siblings were

interested in resources and support groups that they could attend. So maybe future

researchers can look into the resources available that supports them. Additionally, future

research may look into the experiences of siblings below the age of 18. Learning of the

experiences while they are still a child may be of interest.

Advice to Other Siblings

Toward the end of the third interview for many of the participants they shared

some advice that they would give other siblings that have a brother or sister with

disabilities. Here is what they said.

Fashia shared:

Your life is definitely different from others. It all makes sense once you just

accept the sibling for who they are, and accept that. Just accept them for who they

are with their illness, rather than always trying to find an answer. It's like I know that for me and my family, we've been more at peace with it once we've accepted. Not fight it or try to deny it. You just accept it, that your world is not going to be... the same as everybody else. There's this, I don't know the name of the poem, it's an acceptance and commitment based poem. Something like that, talking about it's…you're traveling, you're trying to get to France or something? Yet you get stuck in London. Yeah, and you accept that London is okay too. Yeah, and to me that's what it's about. We've accepted that him being who he is, it's perfectly fine, that's Jacob. I mean just to be patient. It's definitely difficult, very difficult, extremely difficult. It can be very disappointing, and you just don't ... You have a lot of answers as to why it was you that were put in this situation? I think people should be patient, and to focus more on loving the person, rather than fighting what they have. You miss out on the moments you can have. Because the reality is, when the person has an illness, whether it's a mental illness or a physical illness, their lifespan is not as long as an average person. When that time comes and they leave this earth, do you want to reflect back on moments that you spent, like I don't know, trying to figure out everything? Or truly living with that person and enjoying the time you have with them. It's a sibling, or it's a son, just like any other son and sibling. You're to focus on them. I don't know, I just don't want people, because I know how it was for us, when we were just so focused on what's wrong with Jacob. It took away, it clouded the time together. Rather than, Okay, this is what he has and that's that, we're good.

Drew shared:

Patience, patience, patience, patience, love, love, love, patience, patience, love. It takes a lot of patience. A lot of understanding. A lot of trying to understand where they're coming from. Trying to understand that they are disabled and that they are mentally seven years old right now. Just understand that stuff. I'm a strong believer of treating your children the same. It's your child. They might not understand. You might have to approach it a different way. I think if you're telling your son, your non-disabled son, not to punch his little brother, I think you have to tell your disabled son the same thing. He might not understand, but you're just going to have to keep explaining it to him. I'm a strong believer in just treating them the same across the board, no matter if they have disabilities or if they don't disabilities. Understanding the fact that when they do that stuff, you have to have the patience because they are going to do it more often because they do have disabilities.

Nicole shared:

I would say advise them to talk to someone about it. I think that no matter how hard the situation is. I think that everybody that's a sibling or parent could benefit from talking to a psychologist. Just getting that neutral, outside, no attachment opinion. Taking time for yourself, I think, is a huge, huge deal. I'll go to yoga and I can just let it all go. I don't think about any of it. There has to be some outlet for you to do that. Especially if you live at home and you're around it a lot. If you don't live at home it's a little bit easier to go on with life and it not affect your day to day. You need some sort of release. I think just being really open about it is

going to make a big difference in your happiness. I think it's important to spend time with them but it's also really important to not let your sibling affect your relationship with your parents. I think I would tell them about that. No matter how hard it is, you still have to make time to be with your parents, too. That makes a big difference. Getting that attention from them without being compromised by the sibling. Then, doing things together, of course, is important because our lives, parents probably don't realize how much they focus on that one child. How much time they have to dedicate to that one child. I don't resent my parents at all, but I think it would be easy to. You know? If they're not giving you the same amount of attention, you naturally just ... It kind of blows off, you know? Yeah. So, making sure that you don't let it hurt the relationship that you have with your parents or your other siblings. I think if you have other siblings, I feel like it's probably a little easier because you have someone else in that same exact position that you can relate to. If you don't, it's really important to have a good relationship with your parents because they're all that you have besides your sibling.

Summary

After considering the results of this study, I find that there is a need for school psychologists and similar practitioners to consider siblings of individuals with disabilities in terms of a family based intervention approach. This can be accomplished by using more of an ecological model when addressing students' needs. For instance, when a school psychologist is conducting an assessment to determine if a student has a disability the assessment process should include a piece where the siblings of this individual are incorporated. Questions surrounding their interactions with one another should be asked,

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grade and school information of the sibling should be reviewed, and the way the sibling is

impacted by having a brother or sister with a disability should be discussed. Additionally,

resources and wrap around services that can support the sibling should be provided.

Possibly a sibling support group or workshops that discuss what disabilities are and ways

to handle having a sibling with a disability would be beneficial.

Having conducted this study, the holistic view of experiences that siblings of

individuals with disabilities have has been captured. This is a start to a new direction of

research for this population. There may be many more voices that have not been heard

and perspectives that have not been explored. It is important to continue this research.

Here are a few of the final thoughts that siblings shared:

It's a pleasure, it was very nice seeing you and was really happy to hear that

someone is interested in this whole different experience that others go through.

It's a different world, we're not all stamped print out of the same mold. I

appreciate you and thank you for doing that because they have no voice, they can't

speak to you.

I wouldn't change nothing at all because I've always felt my life was a big pot of

stew. All my experiences have made me what I am now but if you have any

spices and you throw any of it off, it throws off the soup. Compared to my life, I

felt it took all that to make me how I see, how I am today.

I just encourage people, when they see children, whether they're at the restaurant

or at the store, wherever they're at, and they see a child that has disabilities, or

they're even making these strong noises, take into consideration that they're still a

human being. They're still a loving heart. Not to judge or get disgusted because

look at them... they're just beautiful children.

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